Emotional Maturity and Well-being: Psychological Lessons of Facilitated Communication

Paul Haskew, EdD
and
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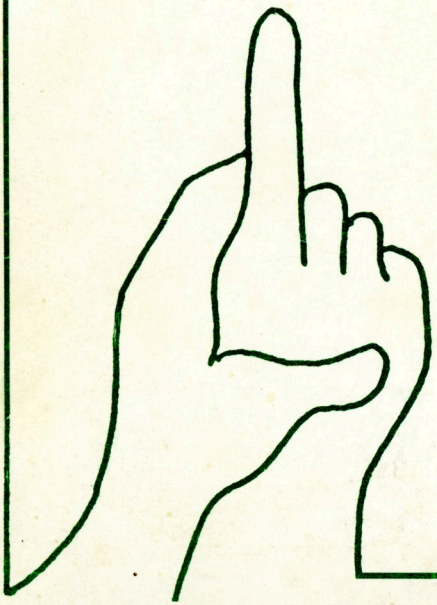

***Movin' On"* Beyond Facilitated Communication**
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"Movin' On" **- Beyond Facilitated Communication** is a series of short books written by clinicians, parents, administrators and advocates, with the cooperation of facilitating communicators, that introduce readers to the changes created by Facilitated Communication. It is the editors' goal to provide up to date information, experience and opinion in a form accessible to everyone interested in the welfare of people labeled developmentally disabled. Many of the topics presented in the series are still being researched by the scientific community. Every attempt will be made to keep the information current, as in a rapidly developing field such as this we believe that all concerned need to share their experience even as we await the research results. The solution to the complex situations we face will come from dialog among practitioners, researchers and consumers. We hope that this series contributes to that dialog.

WATERLOO-WELLINGTON AUTISM SERVICES

Emotional Maturity and Well-being: Psychological Lessons of Facilitated Communication

by

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Some Considerations Regarding Identity Formation, the Hazards of Customary Care, and the Diagnosis and Treatment of Emotional Disorders for Persons with Communication Impairments.

Compiled from Contemporary Accounts of Communicators, Parents, Caregivers and Researchers

'Movin' On" **Beyond Facilitated Communication**
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Editors' Note

Facilitated prose rarely flows flawlessly from a communicator's hand. More often it emerges with an effort marked by many typographic errors. It has been our policy in preparing this manuscript to extend to facilitating communicators the normal courtesy of copy editing in shaping text for publication. Nowhere has the choice of words been altered, but for many quotes spelling, punctuation and spacing has been polished to clarify meaning and eliminate mistyped letters.

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Introduction

What do say, and how do you feel, when a young adult, whose primary communicative activity for a many years has been blurting "irrelevancies" from travelers' directories, spots a picture of the earth on a magazine cover and types, ***"I greatly fear for the ruin of the earth unless humans jointly find a cure?"***

How should a caregiver react when a person who has always seemed totally dependent upon the decisions of others spells out on a computer keyboard, ***"I can talk for myself with Kathy's help. I need for people to talk to me instead of Mom and Dad...?"***

These statements are taken from transcripts of Facilitated Communication. The actual words are completely unlike anything that the 'speakers' had ever uttered before; yet they both have an authentic ring which convinced their audiences that they express the genuine personality and feelings of the communicators.

Perhaps Prometheus' gift of fire to mankind provides the most fitting metaphor for the advent of Facilitated Communication in the worlds of people without speech. Its slow spread through the nineteen eighties, mostly in Australia, was like a fuse that suddenly ignited a bonfire in the nineties. Suddenly everyone was either trying it, talking about it, researching it, denouncing it or teaching it. Facilitated Communication has brought delight, wonder, consternation and a host of other emotions to people who had previously felt little but faint hope and dull fear. Now it seems that Facilitated Communication has enormous potential for bettering the lives of millions of people who have never before had so powerful a voice.

In seeking to share the potential of Facilitated Communication we are not presuming to have unraveled its mystery. But nor do we feel totally ignorant of those processes. We are preparing a series of short books about Facilitation by authors from a variety of disciplines who are doing good work trying to understand both the process and the implications of Facilitated Communication.

This booklet is on psychological well-being, a topic most difficult to write about, but if we are to believe the feedback from parents and others who have read it for us, most critical to address. We are aware that it takes us into uncharted territory insofar as the messages are too new and too few to be sure of the direction this area will ultimately take. But the issues around psychological well-being are too urgent to await longitudinal data. All children and adults, regardless of whether or not the have been labelled, require a nurturing and supportive environment. Moreover, most of these issues should have been addressed before the advent of Facilitated Communication which, perhaps, has given us the gift of seeing what we ought to have seen all along.

As Bill Pensyl, a young communicator tells us, ***"Without the ability to communicate all pain seems greater. Throughout life many of my goals were not attainable: but now they are....I like people to take me and my education seriously. This research has enabled others to understand my intellectual capabilities. And I am grateful. Each person has a lifelong inspiration: mine is to be accepted in whatever walk of life I choose."***

Anne M. Donnellan, PhD
Series Editor

Emotional Maturity and Well-being: Psychological Lessons of Facilitated Communication

I

The Search For Identity

"Before Facilitated Communication my life was colorless, dead. Now it has taken on a colorful glow. Still many shadows, but now I am really alive."

Anonymous communicator

Facilitated Communication (FC) heralds a new era in the understanding and support of persons with communication disorders. Although scientific support for the claims made by facilitating parents, teachers and clinicians has been demonstrated recently by Stephen Calculator & Karen Singer (1992) many researchers remain skeptical regarding its validity.

Others suggest that validity is supported by the wildfire spread of FC wherever it is introduced, by the willing commitment of time and effort (often considerable effort) made to the task of communicating by people with impaired speech, by the mounting transcripts of relevant and idiosyncratic dialogue that are accumulating, and by the profoundly altered relationships that are the consequence of gaining contact with the thoughts and feelings of people previously cut off from the speaking world.

All facilitators make periodic validity checks to satisfy their own curiosity by asking questions to which they do not know

the answers, and have their doubts put to rest by the spontaneous communication of information new to them. While this may not qualify for the scientific record, when it happens thousands of times in hundreds of locations the researchers' tasks should shift from questioning the existence of FC to analyzing the process and pursuing the implications.

There will always be times when messages require validating in order to insure that the individuals are speaking for themselves; the ethical and legal issues are obvious . But there is no further need to see academics embarrass themselves by reporting that they can not document or make predictable a procedure that thousands of people are using with profit every day.

The most significant early lesson of Facilitated Communication appears to be that impaired communication may be caused more by disorders of movement than intellect, and that facilitation provides the help needed for the new communicators to create literary records of thoughts and feelings that have until now been present but unexpressed.

That this is often achieved by people with little or no training in reading or writing is perplexing enough, but the contents of the new communications are apt to be even more amazing. Suffice to say that even peripheral exposure to FC quickly dispels doubts regarding the authenticity of the medium, while exposure in depth raises profound questions about the nature of literacy and what we commonly think of as learning and knowing.

We want to emphasize that by movement we refer here to both physical and mental movements, and particularly to changes in movement. For example, starting to walk, walking, and stopping includes three different kinds of movement. A movement disorder can affect the timing and speed of any or all of them. Similarly, the starting, stopping, and regulating of thoughts, perceptions and emotions may be impaired by movement disorder. Such dyskinesias, to use the

scientific term, can range from the simple to the extremely complex. Typically, they cause trouble at transitions, at beginnings, changes, and stops. Speech requires an exquisitely complex sequence of fine movements compared to which facilitation is a relatively simple process. In other contexts, helping people overcome dyskinesias by touching, restraining, supporting and modeling are commonplace techniques. For an excellent discussion of this concept, and its impact on perceptions of time and space, see Oliver Sacks' text "Awakenings," especially the 1990 edition. Although Sacks writes exclusively of Parkinsonian disorders, many of his observations are relevant in a much broader field of disability.

This booklet focuses on aspects of these discoveries that relate to the first author's experience as a psychotherapist who spent the first twenty five years of his career working with people largely free of developmental challenges coupled with the second author's twenty two years of work in the field of autism and special education. We want to report the degree to which FC reveals aspects of normal psychological development among people with profound communication impairments, and deviations from normalcy in that population that may originate from the customary care provided for people with communication difficulties.

A second goal is to focus attention on preventive and corrective measures that we believe can be taken in the light of all the new knowledge.

It has been our privilege over the past two years to consult with many of the pioneers of facilitation, and to observe facilitation in many different settings, with people showing a wide range of challenges. It has been our privilege, also, to observe the emerging personalities of many of the new communicators. The following are salient impressions we have gathered.

First, facilitated communicators form as diverse a group as the society to which they belong. Their reactions to being able to communicate range from delight and surprise to suspicion and indifference. Some are eager to express things long bottled up, others seem satisfied that they can more easily negotiate everyday life. Many are interested in establishing relationships; others are distrustful of the people around them. In general, however, the new communicators:

1. want to take their places in the larger society as first class citizens with a full range of social and occupational options

2. are acutely aware of the deprivations and exploitations people with special needs experience

3. though without speech, are not out of touch with the world of their peers. They share a "culture of silence"* in which nonverbal communication plays a major role and extends their knowledge of people and events far further than we ever guessed.

*Bob Williams, 1992

We believe that the concept of identity formation is useful for organizing these impressions. Personal, or ego identity is a central construct of Judeo-Christian tradition, and all democratic societies. Individual rights and responsibilities depend upon the belief in a free individual who has a place in, and is part of, a larger society. We believe, too, that Facilitated Communication is showing that many citizens who possessed that status in name only are ready to exert their rights, and accept their responsibilities. But if the history has a lesson for us, it is that none of those rights will be gained without a struggle.

Aspects of Identity

It is generally accepted that a clear sense of personal identity marks the beginning of adult life, and its emergence in adolescence is a necessary period of exploration, experiment and crisis. As a clinician and an academic who have both spent long careers working with children and young adults, issues of identity formation are of daily concern in our work. We see identity as the sum of these parts:

Aspects of Identity

Physical and mental capacities (the available hardware)
Body image
Long term and career goals
Moral values and religious beliefs
Sexual preference and behaviors
Friendships
Group identities and loyalties, and
Leisure activities.

Theories of psychological development seek to chart and explain human growth from birth to adult life, usually by postulating a series of phases or stages through which the individual passes on the road to maturity and the attainment of identity; each stage offering a developmentally appropriate social challenge that must be met before the next stage is reached.

We suspect that the insights that FC provides will result in many theories being rewritten. It now appears that there may be alternative paths to identity for people who lack the opportunities for the social give and take that these theories assume are the building blocks of personal growth.

Facilitated communicators reveals again and again that they share the hopes and fears of all of us to an extent that few dreamed possible, and with implications that many of us now view with a mixture of awe and dread. Even people with verbal skills previously assumed to be adequate for self expression convey greater depths of understanding and sensitivity when their communication is facilitated.

The similarities and some of the major differences in identity formation between "able" and "disabled" persons are outlined below.

Physical capacities and body image

A seventeen year boy, asked how he would describe himself, facilitated the response,:

> ***"My home is my body so I will talk about my home. Creatures have some things in common. My home is my castle."***

This somewhat defensive sounding statement nevertheless reveals the centrality of body image. For virtually everyone identity begins in the mirror. How we look to ourselves, and how we feel we look to others are basic aspects of our sense of self.

Nonverbal people are no less concerned about their appearance. Almost all know they look abnormal or move awkwardly and feel badly about that. A typical comment has been, "I know I look funny, and people make fun of me." No one, especially in adolescence, wants to look strange, so a crucial aspect of personal identity, a wholly acceptable body image, is often beyond reach.

Toewalking, rocking, twirling, twitching, touching, lunging all characteristic symptoms of movement disorder create impressions of people out of control. More global movement

disorders, including ritual behaviors and such improprieties as sexual grabbing, are even more distressing and potentially demeaning. For persons with motorically impaired physiologies - and, again, we believe that such impairments are part and parcel of speech deficiency - such behaviors are unwanted additions to goal directed activities: unpleasant, even painful, involuntary movements or half voluntary self stimulations, that relieve tension or pass the time.

Some communicators have reported that they can limit their most injurious or inappropriate behaviors if they do something similar but less harmful. But often their substitutions are seen by caregivers as other behaviors to be extinguished.

> **One young man who repeatedly bent and broke forks and spoons facilitated that doing so prevented him from biting himself. Until his family knew this they had punished the spoon bending by denying him access to cutlery.**
>
> **Now they are helping him with other distractions, and encouraging him to twist a handkerchief into a knot when he gets tense.**

Facilitation will help us understand more about these dyskinesias, as it reveals the complex persons behind the nonverbal masks. Already communicators who have explained that their bodies do things they can not control command greater respect from their peers. They respond by developing increased self respect, and pay more attention to personal grooming and appearance. In this regard they are wholly like their more able peers.

A major part of body image involves movement. Fluid and appropriate movement, expressive features, and the ability to mirror or complement others' gestures, put us at ease with others and ourselves. Many people who lack verbal ability

suffer other motor deficits. They may have difficulty with major movements, like walking, or minor movements, like smiling; or all motor behaviors may be impaired.

A misleading aspect of motor disorders may be the presence of a repertoire of normal or near normal behaviors, some of which can involve quite intricate maneuvers. It is important to keep in mind when assessing impairments we concentrate on what can not be done, and not use the presence of abilities to argue for the nonexistence of disabilities.

In their efforts to approximate ordinary speech, movement disordered people often make gestures and expressions that may seem to show a sort of maimed immaturity that totally belies their true personalities.

All too often, we suspect, this apparent immaturity causes a drama to develop between the cared for, who perform the roles of insensate children, and the caregivers, who act as long suffering caretakers. The script offers variations of the theme, "If you meet the needs we can not fill for ourselves, we will let you believe we have infantile minds."

> **One example of deliberate helplessness is being played out with some Facilitated Communications. A man admitted to his frustrated family that he had been deliberately making errors with all but one facilitator because he was afraid that if he became fluent with others she would leave him. We suspect his dilemma is not unique.**

Without Facilitated Communication these misconceptions permit their caretakers to ignore evidence of normal human longings, to interpret signs of distress as symptoms of developmental disability, and to deliver as customary care living standards that may be more like a prison than a home.

That all parties are aware of these charades is betrayed by frequent comments like, "He understands everything we say," Occasional reports that nonverbal people could communicate in writing when their hands were supported were never followed up; and those who demonstrated extraordinary memory and/or math skills were dismissed as "idiot savants."

> **A mother told us that this year (1992) she had taken her badly lacerated son to an emergency room where a physician prepared to stitch up his wound without anesthetic.**
>
> **When she questioned him he replied, 'He's autistic, he won't feel any pain."**
>
> **She told us that they spilled as much blood as they dared on his furniture and floor as they left to find alternative care!**

The spread of Facilitated Communication has begun to undermine these misperceptions. It is revealing an entire population that is being betrayed by appearance; like the deaf citizens of Paris whose intelligence was denied until the Abbe de l'Epee deciphered and translated their sign language; and past generations of African-Americans who preserved self respect among themselves but sometimes sheltered behind "Stepin Fetchit" facades.

> **A thirty year old man in a group home widely regarded as humane was distinguished by his penchant for collecting Grateful Dead tee shirts which was indulged by the staff and his parents. A visitor offering him his first chance to facilitate asked by way if making conversation if he really liked collecting the tee shirts. His instant response was, *"No but the staff like them."***
>
> **Asked what he would prefer to receive he typed, *"An education."***

When this man was asked if we could repeat his story without using his name, he replied, *"Yes, if you tell them I have beautiful eyes."* Needless to say, he does have beautiful eyes.

We now suspect that a combination of ignorance, naiveté, and collusion may be supporting a myth of mental retardation. A myth that allows us to believe that people like **that** are not like **us**. That is, they don't act, think, or feel as we do.

This self deception has allowed people and societies to hurt, isolate, dehumanize, and scapegoat a group of citizens whose crime is that they can not reflect back to us the words and gestures our own narcissism would like. Discrimination based on appearance can foster an intensely negative body image among those so disadvantaged. (Recall the importance of the notion "Black is Beautiful" in restoring Black pride two decades ago.)

We do not know how often self-hatred acts as a goad to self injury, but reports from homes and classrooms tell us that sometimes with improved communication comes decreased self destructiveness. An example is young woman whose hands were perpetually scarred from her involuntary bites until she began to communicate. Now she touches a healed hand to her mouth when she thinking something over in a gesture that seems quite natural and benign.

And even more promising is a report from New Zealand about a group of children whose facial expressiveness and body language become more appropriate the longer they have been facilitating. This is also supported in our own experience by a video record we have of a teenage boy who has been facilitating for almost two years. Much of the awkwardness so apparent in the earlier recording has disappeared in recent videos; though we should add that these gains are relative rather

than absolute our friend still wants for grace and fluency in his movement and expressions.

> **A facilitating teacher writes, "Sam and Dave both shared with me the views they had of themselves; their physical limitations, etc. With looking at their own body image they were able to identify limiting factors for themselves. This upset Sam very much....**
>
> **He said, '*I should never have kids...because I would not want to have them feel the pain.*'"**
>
> **She added that this communication brought her to tears while she facilitated.**

So body image is central to identity and self acceptance. In the absence of general social approval, people with unusual appearance or motor deficits may compensate by constricting their lives in some way to create a "comfort zone" in which they can feel at ease. Facilitated Communication has revealed just how small that zone can be for many people, and how hard it is for them to trust people of goodwill who live outside of it. But it has shown, also, that within their comfort zones nonverbal people seem to share the same concerns about appearance, the same pride in looking their best, and the same desires of acceptance that we all exhibit within our own environments.

> **That pain as well as pride accompanies this new awareness was illustrated by a facilitating friend who told us about shopping for new outfits with a young woman whose social circle had expanded as she learned how to communicate.**
>
> **She wanted to abandon the utilitarian camouflage she had dressed in for years. At the mall she chose a new wardrobe of bright, youthful fashions; but when she got them home she was afraid to wear them.**

In the following weeks she slowly gained confidence, and one by one her new clothes and her new identity emerged.

Mental capacity

In everyday life we constantly assess our mental capacities, and maintain a rough sense of where we stand in a variety of intellectual hierarchies. We also assess the mental strengths of the people in our care, and have understandably tended to assume that people who can not communicate and who score poorly on intelligence tests have very low intellectual capacities, an unsophisticated sense of humor and little emotional depth.

From the start FC has called those assumptions into question. Typically, among the first messages typed are, "Mom I love you," "I am not retarded," or, "Tell Mom I'm not stupid." They often go on to underline the truth of these messages with a clever turn of phrase or a pun.

A young man who first facilitated on a communicator made by the Canon company asked, *'Do you have a canon for me?'*.

An interruption broke his chain of conversation so he waited a minute until it was over, then continued, to the consternation of observers not expecting a joke, *'I don't want to shoot myself.'*

Another communicator who offered a particularly deep thought which earned the response, "Wow! that was profound!"

Replied, *'I am a profound motherf....r!'*

With school age communicators, their next requests are often for placements in regular classes. There is now ample evidence that we do well to honor these wishes. In school after school students in special education classes are successfully moving into mainstream classes with the help of facilitation.

The young woman who weathered the task of buying a fresh wardrobe immediately shone in her math class, getting up to speed in algebra in a matter of days.

A parallel development among adults is the demand for homes of their own. "I hate where I live, I don't want to be surriunded by people with autism" is a common refrain of the new communicators. Their pleas for the chance to lead ordinary lives calls into question the whole concept of clustering individuals on the basis of ability or behavior problem.

Enforced silence is not the same as an empty mind. Indeed, it may be the reverse. Shortly after facilitation begins, and the initial concerns have been dealt with, facilitators often report that their communicators have an uncanny ability to know thoughts in their facilitators' minds. Exploration usually reveals that communicators have a well developed "sixth sense" that allows them both to understand what others think, feel, or know, and to transmit their own thoughts to other nonverbal acquaintances, and sometimes to their facilitators.

Many times this sixth sense comes as only a partial surprise to parents and other family members who have long suspected their "impaired" relatives knew far more than could be gathered from simple listening and observation.

Reports that facilitated communicators seem able to read their facilitators' and other people's minds surface wherever facilitation is attempted. We have accounts from dozens of sources in several countries, and the numbers continue to grow.

Skeptics use these reports to argue that facilitators must be the sources of communications, but facilitators themselves say this is nonsense. They see far too many examples of information provided by communicators that they could never have obtained from ordinary sources.

A young man we know told his facilitator what her high school nickname was, and that she had mourned a deceased relative who had been a musician. He was correct in every detail, including the instrument her uncle played, and her feelings about him.

A mother told us about the adjustments she has made knowing that she can have no secrets from her teenage daughter.

And another mother told us that her adult son has no need to hear what she and his other two facilitators want him to know: he simply types his responses to their unspoken comments.

It would be easy to multiply these anecdotes tenfold, but that would not alter the significance of this phenomenon, nor would it help us account for it. Among experienced facilitators its occurrence is no longer controversial; and that it has enormous utility for people without speech is self-evident. But it is a disconcerting talent, nevertheless, and something that those of us who are trying to promote acceptance of facilitation among skeptics would have preferred to deal with at a much later date - perhaps in the middle of the next century!

It may be that a sixth sense is present in all of us at birth, but as speech and locomotion develop the need for it fades. Still, many people seem to retain vestigial psychic abilities, especially at times of accident or trauma, and there is much anecdotal and scientific literature describing these.

For people with impaired communication capacities the sixth sense may remain active and utilized. The speaking world is simply rediscovering it.

Facilitation also reveals emotional complexities that movement disorders often mask. Even though an understandable degree of self centeredness dominates much Facilitated Communication, nuances of humor, caring, sadness, enthusiasm, and many other feelings emerge as trust and confidence build. Indeed there is often a poignant poetry in facilitated messages.

> **Millions of people remember Lucy in the ABC PrimeTIME television program on facilitation responding to a question about being deprived of facilitation typing, *"I fear once again being a clown/in a world that is not a circus."***
>
> **And Jeff, in the same show, *"Loneliness, I am the feeling within the heart/that rips me in shreds/like daggers slicing through flesh."***

While we suspect that some of that poetry derives from verbal rhythms that are developed as an accommodation to motor difficulties, the emotional tones and the original, sometimes quirky, perceptions that are evoked are unique to each new communicator. Sometimes facilitation reveals extraordinarily balanced emotions even in markedly deprived circumstances.

> **A man, Arthur, who we visited at his father's request, and with whom we had the privilege of an extended facilitated conversation, began the communication by asking after our welfare, typing," *How did you like the motel?"***
>
> **He spoke of how he missed his recently deceased mother, and asked for stories about her; told us of how much he cared for his father, and how much at ease he is with the staff member who is his companion.**

He found just the right phrase to respond to a staff member who apologized for past errors, saying, "I didn't know!"

His carefully typed reply, *"Yes I know, Who could know? Together we can learn more for all. It may help us all."* (punctuation added.) But even though he articulated these and many other sentiments he is able to convey through his voice or his body language, gestures and expressions only the crudest of concepts or emotions.

Only slowly are we learning what a profound impediments movement disorders can be, how totally they can mask their victims' humanity.

Long term and career goals

Once one entertains the notion that people without speech are not without intelligence, it is no surprise to find them expressing goals for themselves that parallel their speaking peers. "I want to finish school," "study algebra," "become a doctor," "have a home and family," in other words, enjoy life trajectories of growth, maturation, generativity and contribution.

It is very clear that vastly different expectations are held for people who are born with communication impairments than for people who develop impairments through accident or disease. Where, for example, would astrophysicist and philosopher Stephen Hawking have gained the education that would allow him to inherit Isaac Newton's chair at Cambridge University had he been born with the disabilities he developed as an adult?

Yet we are learning through FC that congenital impairments to communication are not necessarily impairments to innate abilities or potential abilities. Young people tell us of the frustrations of never having a driver's license, of feeling con-

demned to sheltered workshops, group homes, institutions, and segregated care; and doubting they will ever have opportunities to have relationships, marry or become parents. They want their new found communication skills to open doors to careers and family life, and they need allies to achieve this.

A beginning has been made in schools all over the country where students in special education classes are being integrated into regular classrooms. Often they are facilitated by classmates as they take part in the regular curricula. It remains to be seen how far they will progress in our market economy, but some will undoubtedly use their skills in post secondary education and beyond.

> **Anoja Rajapatirana (1992) writes about her son in her local newsletter "Chammi spelled *'Autism held me hostage for seventeen years but not anymore because now I can talk.'***
>
> **"In one sentence he expressed all the agony of the past and his hope for the future."**
>
> **Her son moved quickly from a segregated school to a community based program at a local high school. She adds that he has begun to make friends, and has ambitions of going to college.**

Numerous reports of nonverbal people taking control of their IEP and IPP conferences show that given the tools the job can get done. But decades of custom and inertia will have to be overcome as the gains translate into new, full lives for all people with communication difficulties.

The man whose healthy emotional balance we referred to above asked nothing more than he be allowed to study advanced math. He said he had repeatedly felt frustrated by parents and teachers who could not believe that his abilities

extend beyond the simplest arithmetic when in fact he already knows calculus.

Clearly, it is incumbent upon those of us who can advocate effectively to find ways to bring our facilitating colleagues into the mainstreams of society.

Moral values and religious beliefs

The depth of moral concern, and the salience of religious and spiritual experience among developmentally challenged people continues to astonish facilitators and families. At a mundane level, the desire to expose and redress histories of abuse, especially sexual abuse, is a common early issue in facilitation.

> **One nine year old communicator labeled with "Down Syndrome" stunned his parents at the end of their first long evening facilitating by typing, *"Now is the time for..."* not "bed," as they anticipated, but, *"justice!"***

This is a topic worthy of a chapter in itself, and its importance to communicators is a measure of their concern with fairness and justice, as well as their desire to avoid further harm, but it dovetails with a depth of spirituality and religious conviction that often borders on the mystic.

Communicators refer to talking with God, to the power of prayer, the need for love in the spirit of agape, and to the consolation they gain from religious expression. Again and again facilitators learn of amazingly rich spiritual lives.

> **A man told us, *"Religion is where you can hear angels sing."***

Communicators report about angels who function as protectors, and tell us that life beyond the grave awaits us all. There are reports, too, of darker spiritual forces at work as

well. For many facilitators the ramifications of their communicators' spiritual lives prove profoundly moving, and sometimes frightening. It ranks with the possibility of mind reading as the most disturbing discovery of FC.

We need also to note that when people find their voices and discover the power of words, they give in to temptations to embroider the truth, make allegations against persons they do not like, engage in manipulative behaviors, and in general act a lot like the rest of the human race. They explode yet another myth of mental retardation, that in compensation for their disability they are endowed with a blessed innocence.

Sexual preference and behavior

Despite a widespread belief that people with physical and communicative challenges need not and should not be sexual, sexuality is a frequent theme in FC. Reports of sexually abusive caregivers are widespread, and sometimes very confusing, but normal sexual curiosity and desire is even more commonly expressed, often in extremely graphic fashion!

Facilitators are often embarrassed by communicators' proposals that they share sexual relationships. Judging by the frequency that the topic is raised, one can safely assume that people with disabilities are just as sexually curious as the rest of the population, and may be equally sexually experienced, albeit illicitly and often abusively. Sexual initiations under those circumstances are likely to create much confusion.

> **A young man who was assured that sexual feelings are healthy feelings typed, *"No, sexual feelings are bad, I always get in trouble when I have sexual feelings."***
>
> **Another man, aged 26, who had been placed in an institution when he was six, had a distressing habit of biting people during moments of affection. After yet another of**

these upsetting episodes he facilitated, *"I must solve this problem with kissing!"*

Questions revealed that he had never been kissed, and had no idea how to do it. A quick lesson set him straight. He is now showing appropriate affection, and the biting has ended.

Anecdotes like these show how far there is to go to bring people with disabilities into the sexual mainstream.

A 30 year old man facilitated, *"I wish I was not autistic so that I could talk to you about manhood in the world of autism."*

He continued, *"I will never have a sex life....I want to have a relationship in which someone will look beyond the autism, and love me right."*

There is evidence that longings for intimacy are met in part through nonverbal, non tactile communications, but for many the desire for affection, touch, stimulation and intercourse differ in no way from those of the verbal and able majority; and the frustration of those wishes, coupled with frequent victimization, are a source of chronic and severe adjustment disorder and traumatic stress.

As Facilitated Communication helps people move into the mainstream of life it is to be hoped that their sexuality will also be normalized. In recent years people with disabilities have been coupling and marrying with more societal support, and some are having families. Most, however, feel they can only long for what they doubt they will ever enjoy.

A young caregiver who has established a valued with his facilitating companion told us that the two of them talk about every-

thing, "My girlfriends, my dates. In fact we have the same ideas about female beauty!"

We wondered how much thought he had given to his friend's chances of enjoying anything more than a vicarious sexual intimacy, but we were too shy too ask aloud.

An important part of the changes that we all experience with the advent of FC must be recognition that everyone has a right to the social mixing that encourages friendships to form; and that opportunities for intimacy are normal expectations for everyone.

It is especially hard for parents of teenagers and young adults to back away from total care, and see their deeply loved and especially vulnerable children take the same steps they did, and suffer the same disappointments in love. Yet their sons and daughters want nothing more than the freedoms their unimpaired siblings and peers enjoy.

Friendships

Like everyone else, people without speech seek friends. In particular, they resent spending so much of their time with people paid to be with them, and they are acutely aware of the discrepancies between genuine and contracted friendships. Their sense of personal worth is measured in part by the friends they attract, as it is for all of us.

In particular, people with developmental challenges long for friendships with able peers; not merely for the prestige attached to such attachments, but also to share contrasting talents and viewpoints. Friendships within the nonverbal community are also valued, as are dating opportunities.

An experienced facilitator tells a charming anecdote about first date she helped arrange between two teenagers she works

with. At first they exchanged a series of banal pleasantries via the facilitator.

'Did you have dinner yet?"

'Yes, I ate with my mother."

'It was hot today."

'Yes. Did you go swimming?"

'I love to swim."

Suspecting that she was not party to their real conversation, she asked whether they truly needed her presence in order to communicate. With obvious pleasure, they acknowledged that they had been keeping up the formal talk only for appearances, a more intimate exchange was already taking place through nonverbal channels!

The facilitator excused herself and the happy couple continued their evening together.

Special education teachers in schools where FC is an established practice are discovering to their chagrin that peer groups and gangs are not confined to their verbal students. They are accumulating ample evidence of nonverbal students acting in concert, often when they are not in the same classroom. Sometimes the behaviors are mischievous and add to the sense of fun in the school.

But we have heard a few reports that delinquent and dangerous behaviors are also plotted and acted out. It should come as no surprise that young people growing up in special education ghettos harbor many resentments, or that these find expression in joint behaviors among friends.

A special education teacher told us she found that having students apparently conspire telepathically was the most troubling aspect of their mind reading abilities. However, once she recognized

what was happening she dealt with it as any competent teacher handles an unruly classroom; her students quieted down, and stopped abusing their telepathic skills.

A second teacher, upon hearing about telepathy among students in special education, told us that perhaps it explained a mystery that had long bothered teachers at her high school. Again and again, three students, all nonverbal and in different classes, were found meeting in a stairwell during class hours in violation of school rules. An investigation had established that they each quietly left their rooms simultaneously, as though they were summoned by a signal.

Having friends inevitably means losing friends, and many people in care experience the arbitrary loss of friends and trusted acquaintances through placement changes and job reassignments both of themselves and the people who care for them. Such changes can create immense, and until now, often unexpressed pain. Now that we have been introduced to their silent social world, there can be no excuse for shifts in school or work arrangements of personnel without careful consideration of the student or client's priorities and the social consequences of such changes.

An example of failure to recognize normal grief reactions and the fears associated with unanticipated death occurred recently in connection with the deaths of two children who were in the same school district. One death happened before and one after the introduction of FC to the classrooms. The first child's funeral took place with no involvement of his peers in

special education classes, and none of them attended.

After the second tragedy, facilitated messages revealed that not only had the first death evoked mourning and concern in the class, but that the second caused consternation. Who will be next? the frightened young people wondered.

But this time the teachers were able to help them address their concerns and emotions, and some students were able to go to the funeral. Months later memories of their lost comrades are common themes in their facilitated conversations, but appropriate discussion helps move along their steady recovery.

Again, it seems probable that movement disorders impair the expression of emotion. Forming appropriate facial gestures is difficult or impossible, but movement also involves timing, and there is much evidence that an inability to fall into the social rhythms we take for granted also creates the impression of being nonsocial. While caregivers often try to teach appropriate social cues, small talk and flirtation are difficult to describe or to teach.

Paradoxically, a third stumbling block may lie in the ability to both hear what is being said and sense what is being thought. Getting conflicting information and then having difficulty responding to it is likely to be a monumental obstacle to ordinary social interactions. Recently published interviews by Laura Cesaroni and Malcolm Garber (1992) with two verbal persons with autism reveal their frustration at being viewed as unsociable when they are well aware that people they might befriend will say one thing while thinking the opposite.

And as high school student, Bill Pensyl, writes (1992), *"People believe I am the*

ignorant one when I read their body language instead of talking. People still cannot see my potential."

He continues, *"Progress is being made everyday that I am receiving an equal education."*

Yet the desire for friendship, remains; and now, perhaps, the way is cleared for it to be met far more often and successfully.

A facilitator gossiped to us, "After speaking to a large psychology class at the local college, Faith was asked by a handsome longhair, 'Do you like music? Who are your favorite bands?'

'Well, I've only been exposed to top 40 rock, maybe you teach me about other music!'

It turns out the guy plays six instruments! They exchanged phone numbers to her Mom's panic! Yesterday he called, and they have a date on Monday."

Group identities and loyalties

Much of our sense of identity derives from family and community. Feeling part of our town, our school, and our church, or a fan of our favorite ball club all contribute to our sense of self. People with disabilities are no different, but all too often there is a negative tone to their identifications. The classes and agencies they are members of rarely instill much pride.

Even well meaning organizations like the Special Olympics emphasize the separation not the integration of people who are different.

Facilitation reveals that there is an ubiquitous longing for a greater sense of place in the larger society; a deep desire to move beyond the association with disadvantaged peers to

valued positions in families, church groups, social organizations and institutions of all kinds.

A young man of our acquaintance whose first facilitated statement was:
"I can't make words in sounds, can I type words?" **has become an avid baseball fan since his world opened up.**
He can often be seen at the local ball park commenting perceptively on the passing scene using a battered letter board.

At a recent conference we enjoyed hearing from a facilitating panelist who is serving on councils and committees, consulting and traveling, keeping up an exhausting round of advocacy activities; none of which she could have considered doing prior to the introduction of Facilitated Communication.
We would have liked to hear her reflect on the evolution of her sense of identity in the past year, but she was too busy to take time for personal questions.

Leisure patterns

Closely related to group identifications are individual notions of what is pleasurable, relaxing and fun. Surprisingly large numbers of communicators take pleasure in poetry and art as well as showing interest in science particularly physics and astronomy. Well developed aesthetic sensitivities emerge frequently in FC, as does an intense awareness of the nature of life and living.

Developmental disability in no way inhibits the desire to pursue happiness, but often has crippled the means. Now a way has opened up that may allow a presently disenfranchised segment of society to enjoy a whole panoply of activity previously denied it. As that happens, a rounding out of individual

identities may occur to enrich our society with talents and insights hidden since the dawn of literacy.

The flood of personal opinion and information that FC generates again indicates that communicators see themselves in much the same fashion as the less challenged, temporarily able majority. It shows that their perceptions, hopes and fears are colored by the same range of emotions and longings as the larger community. This is the good news.

Set against it is the stark reality that too often their customary care still undermines their self worth and discourages their search for a secure sense of personal identity.

> **Mike, a twenty three year old man who now conducts his own IPP meetings noted that he wanted to, *"Live with one person, not autistic!"***
>
> **At a follow up meeting his mother said she wanted him on a diet.**
>
> **He responded, *"No diet!"***
>
> **"Then you will have to do your own cooking," said his mother.**
>
> ***"No cook, want a maid"* he joked.**
>
> **Mike made it clear that he intended to take care of his treatment. He refused to leave the meeting during the strategy session, forcing the staff at his residence to develop their behavioral program in his presence.**
>
> **A staff member asked in a tone he heard as disparaging, "Mike, how do you see yourself?"**
>
> **He replied, *"In the mirror!"***

Being able to communicate should mean being able to take greater control of one's life. Facilitation has begun to accomplish this for many people, but too often promising

beginnings fail to mature into concrete changes. John, a particularly fluent 30 year old communicator, invited us to use excerpts from his plans and testimony for his annual planning meeting:

> ***"I am very intelligent but I understand that people think I am retarded. But I am not, I am autistic. I cannot control some of the things that I do sometimes. I need for people to understand me....***
>
> ***I need to begin to speak out for myself about what has happened to me at the home and how I feel about it. This will help me."***

John wrote a letter to his team, and opened the meeting by having it read. It begins:

> ***Dear Team Members:***
>
> ***I am writing this letter to introduce Kathy. She is my friend and facilitator. She will be talking for me during the meeting.***
>
> ***I would like it if you would talk to me instead of Mom and Dad. I am able to speak for myself with Kathy's help. It is important to me that you talk to me.***

John's letter went on to detail matters of concern to him, and the planning meeting went slowly forward. Despite his direct and repeated request to be spoken to and not to be spoken about several team members repeatedly, and one consistently, spoke as though he was not present.

> **John's request for a job placement was noted but never acted upon. Six month's later he was asked again what he would like to do. *"Work in a nursing home with old people"* he facilitated. *"I told you that in May."***

II

Adjustment Disorders and Communication Impairments: The Impact of Facilitated Communication

Even though we now have evidence that people without speech, or with the misleading speech characteristics of movement disorders, are nevertheless capable of a fully developed identity, the environments, interactions, and expectations of their customary care often continue to reflect assumptions that they are incompetent and insensitive. Though many are treated with respect, others, seen as incapable of comprehending respect, receive little.

When the institutional response to disability is to meet little more that physical needs for shelter and nutrition a stunting of psychological growth is inevitable. The same isolation and numbing routines dog the lives of people in custodial classes and adult day care. They rarely experience the give and take of normal social events as they are shepherded around in cocoons of special education classes and sheltered workshops.

When people diagnosed as disabled are addressed, it is often with a question the speaker already knows the answer to, or an instruction aimed at changing their behavior. Again and again they hear themselves discussed by caregivers, including parents and family members, as though they were not present, as though they were nonpersons, and as though the caregiver knows exactly what they want, what is good for them, and what they should get more like house plants than people.

A mother of a sixteen year old told us that five of seven students in her son's high school class are facilitating, and all five have shown themselves to be capable of age appropriate conversation.

But the classroom curriculum has not changed. Day after day they are expected to facilitate their names, addresses, telephone numbers, and other simple set work. Not surprisingly, they are getting slower, not faster, and a variety of four letter words and sexual references are appearing in their scripts.

In such depersonalizing circumstances, where every aspect of identity is minimized, (In the example above, even dentity itself is used in a dehumanizing way.) the struggle to achieve a complete sense of self is especially difficult.

The psychiatric profession acknowledges that an inadequate sense of identity constitutes a disabling disorder that is associated with multiple symptoms of distress. It provokes variable moods, indecision, distrust of self and others, oppositional behaviors, and a focus on the immediate at the expense of the future.

Persons with identity disorder are not sure of what they think, are easily swayed by arguments, and may latch on to and abandon ideas and ideologies almost whimsically. We have noted that an additional problem for people who seem to retain the ability to share thoughts nonverbally is that sometimes they are not sure whose thoughts they are expressing. They seem to have particular difficulty knowing whether thoughts are their own or their facilitators' (a problem that can interfere with validation experiments), but with practice and attention they learn to discriminate, and in doing so firm up their own sense of identity.

When identity disorder is coupled with minimal care environments that covertly tolerate exploitation and abuse, the stage is set for the kind of intolerable stress that leads to the development of adjustment, conduct, and traumatic stress disorders.

It has been estimated that sexual abuse rates for children with disabilities are four to ten times the 25 percent rate for the general population. That means, claims Nora Baladerian (1991) that there is a better than 100 percent likelihood that a disabled child will be molested before he or she is eighteen. Facilitated Communication is confirming those statistics. We can safely assume that other forms of abuse are at least as commonplace.

Perhaps it is no coincidence that the psychiatric disorders have many symptoms traditionally associated with developmental disability: repetitive behaviors and rituals, hypersensitivities, anxieties, depressions, sleep disorders and failure to thrive among them, are also characteristic of adjustment and traumatic stress disorders.

Investigating the extent to which affective and anxiety disorders contribute to the symptomatology of pervasive developmental disorders is a research program that may be hugely assisted by Facilitated Communication in the near future.

At present we are largely extrapolating from clinical data and assuming parallels with traumatic stress in verbal people. We know that the kind of arbitrary shifts in living circumstances that are commonplace for people in care can induce psychiatric disorders in the population at large. Separations without explanations, unannounced medical treatments, unchanging routines of work, or unexpected employment and residential moves, extended periods of forced inactivity, and punishment for behaviors that cannot be controlled are familiar examples of interventions that traumatize "normal"

individuals, but may be considered ordinary aspects of care for people with disabilities.

People without speech are easily victimized. Before FC, information about abuse by caregivers was hard to obtain and often impossible to corroborate, even though many people believed it to be widespread. Facilitation partly opens the curtain on abuse.

Partly, because FC does yet not constitute evidence readily admissible in court - nor is it likely to without major and unforeseen advances in validation. But facilitation does give victims a voice, and what we hear is that violence and rape are everyday hazards, and a major source of anxiety for people who can not call attention to their plight. Young and old tell about severely traumatizing abuse to which they and others are subject .

> **A mother called us to consult about her adult son whose facilitated communications included repeated accounts of sexual abuse he suffered in a group home.**
>
> **She wondered if she was observing perseverative behaviors or whether her son just needed to tell his story over and over again to come to terms with his feelings about it.**
>
> **While we had no definitive answer, we could not help but note how similar his behavior was to that of other adults who recall childhood abuse.**
>
> **Follow up calls confirmed that facilitated psychotherapy had helped her son move on to other issues of concern.**

Such are the vagaries of FC at this time, it may be sometimes difficult to know when they spell out these accounts whether we are reading about a personal experience, an observed

trauma, or the nonverbally communicated experience of a friend or acquaintance.

We can be confident, however, that abuse hurts people who can not communicate as much as it hurts those who can; that abuse of one person may traumatize many others; and that the presence of abuse creates similar symptoms for people everywhere.

One rare but particularly distressing psychiatric condition, Multiple Personality Disorder, is generally believed to be a reaction to severe and prolonged childhood abuse. There is evidence of MPD in the transcripts of some communicators. While caution is always needed in interpreting information of this kind, there are reasons to suppose that MPD could be more common among people without speech, and with other impediments to securing assistance. Helpless victims of abuse, usually children, are most likely to develop MPD - a compensatory condition in which a variety of distinct personality fragments seek to cope with circumstances and memories too traumatizing for one wounded ego to bear.

In her best-selling autobiography of a person diagnosed autistic, Nobody Nowhere, Donna Williams describes how she employed two personalities to protect her incredibly sensitive inner self. One is a compliant, overtly sexual young women, the other a cruel, suspicious and self protective character she called Willie. Together they weather the storms of adolescence and the hardships of living without family support. She is not describing multiple personality in the psychiatric sense, but she does show how changing identities can be adaptive for a person with communication problems.

As we noted above, in a world where the spoken word is not necessary for communication to take place it is not always clear whose ideas are being facilitated. Sometimes a communicator simply defers to the thoughts of a person with more perceived authority, like a facilitator, teacher or parent. But sometimes, we suspect, a communicator may become a "channel," typing an account of another nonverbal person's trauma. Careful questioning and cross-checking can minimize the confusion of multiple "voices" in one communicator, but their existence generally indicates the presence of major disturbance in the communicator's past or present circumstance.

Another consequence of abuse that creates problems for mental health professionals is that victims sometimes develop the conviction that they are possessed by a demon or devil. Although very unusual, when this does occur it is often associated with symptoms of MPD; and where "alters" (the term used for multiple personalities) leave off and "demons" begin may well be more a matter of opinion than established medical diagnosis.

Given the intense spirituality of many communicators, and the religious beliefs of their families, such evidence of "possession" can be very alarming. When coupled with suspicions that satanic cults actively recruit members who work in caretaking occupations, a truly frightening combination of symptoms, beliefs and hazards may occur.

There are very competent therapists and pastoral counselors who work at this interface of religion, psychiatry and crime, and people caught in these awful webs need not feel helpless. But care and much consultation in choosing helpers is essential if interventions are not going to further complicate the problems.

While being aware of the existence of such troubling issues as MPD and possession can forearm us when dealing with them,

more mundane emotional distress is far commoner. Depressions and anxiety states, phobias, inhibitions and obsessions, behavioral and conduct disorders: these are the symptoms of emotional disorder we most often encounter. These are what create the most pain in all people's lives. Fortunately they are also the most easily relieved.

Competent therapists from many branches of applied social science can promote recovery from these conditions, usually without medications. But for people without speech these problems may be disguised or invisible. Or worse yet, considered to be symptoms of their developmental disabilities. In the next section we discuss what can be done to bring relief.

III

Treatment Issues and Facilitated Communication

In human affairs problems are usually easier to identify than to solve; and that is especially true for people with special needs. Even in the larger community many emotional problems go untreated, and many more are not even diagnosed. Nevertheless, parents, schools and other agencies across the world are rising to the challenge of providing relief for their relatives, friends, students and clients who are expressing their pain and their desire for change for the first time through Facilitated Communication. As in the larger community, effective intervention involves amelioration, prevention, and treatment .

Amelioration and prevention both work to reduce the incidence and risk of psychological distress by changing the environments of care and the attitudes of the caregivers. They are by far the most effective ways of improving overall mental health. Most problems of adjustment resolve themselves when the stressors that produce them are removed.

In pursuit of this goal, most important of all is extended consultation with the persons involved. Only they know what they need and want, and what bothers them most about their living situations. Facilitation provides the means for far clearer understanding of these requirements and desires, and the degree to which they can be met is a measure of the health of their environment.

Eliminating the inherent abuses of institutional living will go a long way toward promoting mental health, but we know,

too, that even people living at home face fears and hazards the more able of us easily avoid. The long term security and care of adults, for example, cannot rest on parents' shoulders; yet often parents are their only true advocates. Hard pressed family members who have sacrificed years of their lives can themselves be abusive at times; especially when there is no respite, and little money available.

So the primary goal for mental health remains the provision of respectful, responsive, and supportive living arrangements that do not rely solely on the family.

The difficulty of forming friendships is often cited by parents and communicators as a particularly painful part of living with a disability. Now we know even more clearly how galling it can be to have something to contribute but no way to make that known.

We see, too, that facilitators often become true friends and mentors of the people they assist to communicate. But when facilitators remain their only friends such closeness can become a burden. Nevertheless, they serve as powerful examples of the opportunities that exist for expanding our social communities by including people never before known to be interested in joining, or able to participate.

Clearly the key lies in enlarging the circles of friends around communicators by working hard to introduce more and more people to facilitation, and seeking more and more ways to bring communicators into the social mainstream; in clubs, bars, churches, political parties, special interest groups of all kinds; anywhere that people gather to share ideas and opinions, and to seek and provide mutual support.

Treatment for emotional disorders.

In addition to a secure sense of home, community, and commitment, people who have been abused require restorative care to overcome chronic and acute emotional illness. This is

a field which attracts a growing number of practitioners treating patients with speech. But few of them have experience with nonverbal therapy, so there is as yet a meager knowledge base. A few pioneers offer individual treatment in scattered locations, and a substantial number of other therapists offer consultations and short term interventions of dubious lasting value. But the introduction of Facilitated Communication on a large scale may change everything.

Now there is a possibility of providing effective therapy for more clearly defined problems. While the best ways to deliver such care are still being worked out, there is no reason to delay the search for solutions; any motivated advocate can negotiate for psychological care with practitioners who are willing to listen to the problems.

> **We received a call from a residence director asking for guidance after he had learned that a newly facilitating boy in his care was contemplating suicide.**
>
> **We asked what had already been done and were told that the staff had immediately expressed their concern, that his parents had been notified and had made a supportive visit, and that he was being provided with as much opportunity to facilitate as could be mustered.**
>
> **The director noted that already the boy had indicated he felt less suicidal, which did not surprise us, given the prompt and appropriate response.**
>
> **Our advice was that the director talk with staff about finding a local mental health counselor who they would feel comfortable consulting, and work from there in meeting both the needs of the moment, the appropriate care for the boy, and in**

reviewing the overall psychological health of their facility.

Individual counseling and psychotherapy traditionally provides for private and confidential conversations between client and therapist in which a gradual build up of trust and understanding leads to a clearer sense of self, a testing of new ideas and beliefs, and a gradual abandonment of symptomatic beliefs and behaviors.

Unfortunately, neither privacy nor confidentiality can be reliably secured with Facilitated Communication. Until a therapist becomes adept at facilitating, privacy is compromised by the presence of a translating facilitator, who may occasionally be a contaminating influence in the communicator's world. Even when a good facilitating rapport has been established with a counselor, the "sixth sense" that people without speech often possess can potentially interfere in the relationship.

Despite the potential problems with privacy the demand for psychotherapy remains real and pressing. Both communicators and their families want help overcoming the legacies of abuse, working out the developmental issues of adolescence, and coming to terms with the inadequacies of customary care both within the family and in the group home.

And despite the hazards and difficulties, there is a clear call for something close to ordinary counseling; a dialogue with a trusted, trustworthy yet disinterested person. Someone who is informed, secure, empathic, and available. Especially available! All persons with disabilities have experienced abandonment by people they cared for and trusted.

A parent of a daughter labeled autistic who has lived at home all her life remains painfully aware that, because of the difficulty she has making friends, even her superbly cared for child has experienced re-

peated abandonment by people who have earned her affection. Staff who have worked with her left for other jobs, and friends she has made have moved and do not call or write because of the difficulty of communicating with a person who neither talks nor writes freely.

After reading a draft of this booklet she urged us to underline our concern that counselors for people with communication impairments recognize from the beginning the extra responsibilities they may be undertaking.

So a willingness to counsel must include a commitment to being available in both the short term for unexpected crises, and the long term to allow time for recovery to take place. Although no guidelines presently exist, it seems quite clear that counseling with FC needs more than once-a-week availability, and far more than the six to twenty sessions that most insurance carriers deem adequate for their policy holders.

Many times the first people who help are the facilitators, regardless of their training. As trusted able adults they are the first to hear of problems. When a problem shared becomes a problem halved, issues raised with facilitators are resolved without further intervention. But facilitation is stressful work. Facilitators find themselves bearing the burdens communicators share with them. Support groups where they can talk about these pressures (with appropriate safeguards for communicator's privacy) can help them cope with both practical and psychological aspects of their work. Knowing when to handle matters alone and when to seek outside help is a judgment call that should not left in inexperienced hands. Facilitators also need to know where there are professionals they can consult with as the needs arise. And as more people

are drawn into meeting these needs so will the knowledge of what works and what does not work will develop.

What is surely **not** needed is indiscriminate medication treatments that have the covert goal of making people "manageable" by robbing them of their senses. With FC there is another weapon to battle the forces eager to provide custodial care with a minimum of activity and maximum of "tranquillity." People in pain want to solve their problems, not seal them over with chemicals. Given what we are learning about ultra-sensitivity of people labeled autistic, and the traumas of their customary care we should be very cautious about agreeing to drug treatments for symptomatic behaviors.

So who will provide the therapy? The answer, most likely, is anyone who will meet the challenge of working with a person who is nonverbal. That does not mean the unqualified or second rate, but rather counselors who will put service before profit. They will be drawn from the ranks of many allied professions, and their worth will not be measured by their degrees or their fee scales, but their empathy, understanding, and their availability.

Very likely all counselors working in this new medium will want to consult with colleagues who have experience with diagnosis or trauma; and as their numbers grow they will meet regularly to discuss their work and to offer peer supervision and support to each other. We hope that someday no therapist will be considered well prepared who does not know how to respond to a person who can not speak.

IV

In Conclusion

We face a curious challenge. A population for whom we have traditionally advocated seems suddenly capable of self advocacy. Yet their need for caring allies may now be greater than ever. Communicators' credibility is challenged as their expectations rise, and they become more vulnerable as their familiar defenses against intrusion are broken down circumstances which may induce increased distress, and more acting out. In turn, they may experience repressive reactions to their anger and frustration, resulting in a widened credibility gap, and even successful calls to ban Facilitated Communication.

Now that effective individual communication is possible, individualized personalized service becomes crucial. No person belongs solely in the company of people grouped and devalued because of their disabilities, and their paid caregivers. All of us deserve a place in the larger community, and a share in the services that community enjoys.

An African proverb says, "It takes an entire village to raise one child." Our challenge is to find the means to provide each person with special needs a healthy home in our global village, and to welcome the new gifts people are offering as they are liberated from silence.

Postscript

We close with the following comments from Kanwal Searha who was facilitated by Martha Leary in Toronto, November 4, 1992.

> *"Now a few words from one who uses the assistance of another person to communicate.*
>
> *For years I dreamed of finding a way to let people know I had feelings.*
>
> *The most unique feature of humanity is the ability to speak out loud: this is both a blessing and a handicap.*
>
> *The blessing means that people of all races can negotiate their differences through verbal dialogue.*
>
> *The handicap means that often those who do not speak out loud are not considered human.*
>
> *As the truth about our diversity of gifts becomes known to more people we can begin to join the others.*
>
> *Sometimes we will be thought of as deserving more opportunities for learning.*
>
> *The significant change will occur when people realize what we can teach.*
>
> *This is my new dream."*

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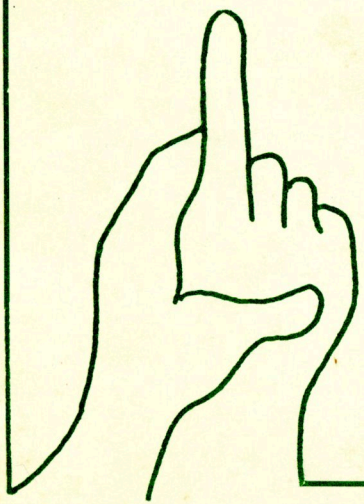
"Movin' On" **Beyond Facilitated Communication** is a series of short books written by clinicians, parents, administrators and advocates, with the cooperation of facilitating communicators, that introduce readers to the changes created by Facilitated Communication. It is the editors' goal to provide up to date information, experience and opinion in a form accessible to everyone concerned about the welfare of people labeled developmentally disabled.

Emotional Maturity and Well-being: Psychological Lessons of Facilitated Communication reviews what we are learning about the inner worlds of people with communication problems, people who could never before tell us what they think and feel, celebrate and suffer. Illustrated with numerous first hand accounts and facilitated statements, this slim volume heralds the arrival of an entirely new psychology of disability.



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